

# Interactive Behavior Change Technology to Support Diabetes Self-Management

## Where do we stand?

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### The growing imbalance between need and resources for diabetes care

The number of people living with diabetes continues to rise at an astounding rate (1). Moreover, the epidemic of childhood obesity, coupled with widespread intake of high-fat, low-fiber diets, suggests that this problem will not abate in the foreseeable future (2). Even if the number of diabetic patients miraculously held constant, the need for diabetes medical management and self-care support would continue to trend upward. Diabetes treatment and outcomes have improved over recent years (3–5), and, like the population overall, patients are living longer. Meanwhile, expectations for diabetes care are increasing, with clearer standards for what self-care support should include (which is a good thing [6]), as well as increasingly aggressive goals for physiologic targets such as A1C and blood pressure (which has been more controversial [7,8]). Payers for health services are having an increasingly difficult time funding diabetes care. Experts agree that the current Medicare program will be insolvent in less than 20 years (9), and mounting costs on private insurers have led them to increase cost sharing, limit eligibility and benefits, and even close their doors completely. Insurers pass these financial pressures onto both service providers (through lower payments) and beneficiaries (through higher co-pays and fewer benefits), making out-of-pocket cost one of the major barriers to

effective diabetes management (10,11).

In short, we now face the untenable situation of a growing demand for diabetes services, coupled with fewer and fewer resources to pay for it.

Meeting this challenge requires addressing some of the most complex problems in health care, including how to coordinate diabetes services across providers and how to provide effective support for self-management between outpatient visits. The Chronic Care Model is now accepted worldwide as a blueprint for how a transformed system of care should look (12), and diabetes educators and care managers have been a core resource in the vision for reshaping services so that they prevent, rather than just treat, patients' diabetes-related complications (6–13). Unfortunately, care management programs and diabetes education services often struggle with staffing shortages, limited funding, and competing time demands (14–16). Even under the best of circumstances, clinicians cannot provide the day-to-day support that many people with diabetes need to proactively address self-management problems. As a consequence of both resource constraints and acute care-oriented health systems, providers often spend their time only with patients who are either newly diagnosed, in crisis, or the most assertive in advocating on their own behalf. To meet the growing need for diabetes care given these realities, health systems must take a broader approach

that views patients' care in the context of their social network, culture, and community (17).

### Interactive behavior change technology as a partial solution to the looming crisis in diabetes care

Interactive behavior change technology (IBCT) is one potential resource for improving the effectiveness of diabetes management programs given the very real limits on funding and staffing time (18). IBCTs include the use of hardware and software to promote and sustain behavior changes (18). Examples include the use of PDAs, patient-centered Web sites, automated telephone calls, DVDs, and touch-screen kiosks. In general, these tools 1) assist patients and their clinicians in monitoring changes in health and self-care needs, 2) support patients' efforts to make behavior changes by promoting health and effective self-care, and 3) enhance communication between patients and potential supports for their disease management. Other types of technologies such as physician-targeted clinical decision aids, electronic medical records, and disease registries can also support quality diabetes care, but these tools are usually considered separately from IBCT because they provide information solely to the clinician and represent a more passive repository of data rather than a proactive effort to change behaviors.

Some IBCTs are designed to assist patients in being more independent; thus, patients can improve their self-management without assistance from their health care team. For example, resources such as electronic medication reminders, meters that provide longitudinal records of patients' glycemic control, and PDA-based calculators to monitor intake of various nutrients may assist patients with self-regulation and serve as important cues to action. While these tools can be valuable, there are limits to many patients' ability to manage their diabetes on their own, even with technological supports. Just as the concept of doctor-centered care has given way to a greater emphasis on "self" care, improve-

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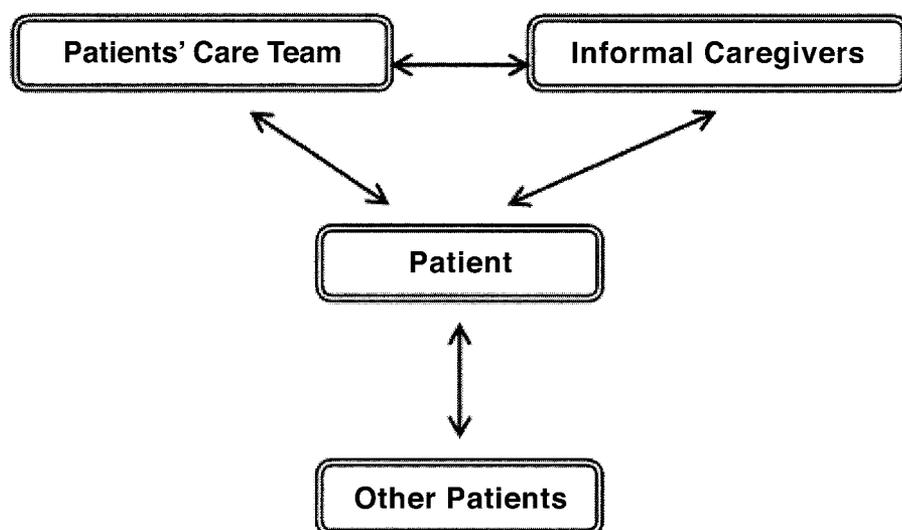
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**Abbreviations:** IBCT, interactive behavior change technology.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

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**Figure 1**—Communication links that could be targeted by IBCT.

ments in diabetes services will require another shift in focus, recognizing the contributions to self-management support that are and could be made by the broader network of human resources in patients' lives (Fig. 1).

Computers and the Internet have emerged as an incredible resource for enhancing communication, and the strength of many IBCTs is that they can strengthen the potentially critical communication linkages that are shown in Fig. 1. Much of the research on IBCT has focused on improving communication between patients and their care teams using services that allow clinicians to review patients' status and deliver educational messages between face-to-face visits. Other IBCTs have sought to build connections between patients, often using Internet chat and e-mail to enhance mutual support (19–21). Far fewer studies have explored ways to use IBCTs to enhance diabetes-specific support that is available through patients' informal caregivers. Although caregivers play a central role in many patients' diabetes self-care (22), few if any studies have developed IBCTs that provide these caregivers with a structured communication link with the patients' health care team.

Several reviews of IBCT applications to improve chronic illness care have been published, and these generally have been positive. One systematic review of randomized trials found that computerized educational programs improve diabetic patients' diet and metabolic indicators (23). Other reviews, including one by the Cochran Collaboration, have concluded that IBCTs can improve end-users'

health-related knowledge, perceptions of social support, self-care behaviors, and clinical outcomes (24–26). Seminal trials have shown that relatively straightforward services such as e-mail–delivered nutrition counseling or clinic-based kiosks used to identify behavioral goals can improve patients' cardiovascular risk profiles (27–29). Commentaries reflect the widespread enthusiasm for these technologies' potential to address the ongoing deficiencies in diabetes self-care support (30).

#### So what's the problem?

Given more than 10 years of research and the many champions of IBCT, why are these services not more broadly translated into improvements in real-world diabetes care? Most health systems offer very limited IBCT services to their patients, and payers continue to drag their feet on supporting broader implementation (31,32). Despite the enthusiasm among some experts, several very real challenges have limited broader adoption. In research studies, user discontinuation of IBCTs is the norm. In fact, deterioration in program engagement is so common that one author has coined the term “the law of attrition” to describe it (33). Fifty percent reductions in log-ons to health Web sites are frequently reported in research studies (19–34), and dropout rates higher than 90% over less than 1 year have also been observed. One study suggests that behavioral intervention programs delivered over the Internet may reach those who need them the least (35). While that same study also found that obese patients were more likely than normal-weight pa-

tients to participate in Internet weight-management services, one has to wonder whether this is much consolation (36). In one of the few long-term studies, investigators found that only 26 of 58 patients used the Internet to enter self-care data and communicate with their physicians over 3 months, and only 4 continued using it after 3 years (37). Most Web-based programs simply do not provide services that are accessible and useful to many patients, particularly those who do not own a computer, speak languages other than English, or have health literacy deficits (32,38,39). Moreover, a systematic review of 55 randomized trials found no good evidence that telemedicine services were cost-effective, and many large payers are reluctant to invest in these interventions without firm evidence of cost savings (40). While “cybermedicine” may not be killing you (41), there remains enough skepticism among patients, providers, and payers to slow the adoption of IBCT and the development of more effective models.

#### Some examples of new approaches

Despite these concerns, even skeptics of IBCT should agree that given the looming crisis in human resources for diabetes care, these technologies are worth an ongoing thoughtful examination to learn how they might be useful. Unlike usual clinician-delivered services, IBCT has the potential to reach patients who are poorly served by standard outpatient diabetes care. If appropriately designed, IBCTs can deliver diabetes education and monitoring of consistent high quality across patients, clinicians, and health systems and may alleviate the pressures on patients' care team to provide all of the services patients need during brief outpatient encounters. IBCTs can be available to patients where and when they need help and can link patients with resources (e.g., other people with diabetes) that would not be easily accessible without these tools. In short, IBCTs may improve diabetes care through not only increasing patients' access to the types of services available from their health care team but also by providing completely new resources for helping them cope with their self-care challenges.

One way to refocus the discussion about the potential value of IBCTs is to shift from an emphasis on specific IBCT tools such as the Internet or PDAs to a focus on the functions we would like to see IBCTs serve in diabetes care. Ongoing

work to develop IBCTs is in fact exploring ways to leverage the broader range of human relationships shown in Fig. 1, and the following sections briefly highlight some examples.

### **Using electronic refill data to promote medication adherence and intensification**

Medications are critical to effectively manage diabetic patients' glycemic control, lipids, and blood pressures. Unfortunately, providers often fail to initiate or adjust medications to optimum effectiveness (42,43), and patients' problems with adherence are widely recognized (44–46). Because most prescribing decisions are made without any objective data about patients' adherence, it is usually impossible to discern whether poor physiologic outcomes signal the need for adjustments in the regimen or whether more patient support is needed for keeping adherence on track. Even the most diligent patient can have difficulty conveying the details about their use of multiple daily treatments, and physician estimates of patients' adherence is little better than chance (47–49).

Researchers are examining ways to use information in large electronic medication refill databases to support both patients and their clinicians in making decisions about treatment adjustment and adherence support (50,51). Because more information alone is unlikely to improve outcomes, researchers are exploring the most effective way to link objective adherence reports from refill data with behavioral counseling by clinical pharmacists and other health professionals (52–56). By using already collected refill information to support established clinical relationships, these IBCT interventions are designed to improve the quality of diabetes adherence counseling without adding additional clinicians or requiring patients to access health information in new ways.

### **Promoting walking with enhanced pedometers**

Physical activity is essential for diabetic patients' weight management and cardiovascular health (57,58), but interventions promoting activity have either been ineffective or too resource intensive to be feasible in real-world practices (59). Pedometers may assist diabetic patients in increasing their walking by providing objective feedback on activity levels (60,61). However, pedometer use (like

medication adherence) is difficult for patients' health care teams to monitor, and some clinicians fail to encourage activity among their diabetic patients because of concerns regarding cardiovascular risks. Tailored behavior change messages may enhance the potential benefits of pedometer use (62) but are rarely used effectively by patients' primary care teams.

The Veterans Walk for Health Study is an ongoing multicenter randomized controlled trial investigating the impact of two different modes of pedometer step-count feedback on patients' walking. Older patients with cardiovascular risks are being recruited from five Veterans Affairs health care systems nationwide and randomized to standard nutritional counseling or either 1) nutrition counseling with a simple pedometer to help with walking self-monitoring and goal setting or 2) nutrition counseling with an enhanced pedometer that captures detailed time-stamped step-count data. Step counts are uploaded from the enhanced pedometer to a Web site, and during sessions with a nutritionist, participants can review detailed graphs of their activity along with tailored messages designed to encourage progress. The study is part of a larger program of research called "Stepping Up to Health" that is developing comprehensive physical activity interventions, including enhanced pedometers and Web-based communication, in order to link objective feedback on patients' behavior with targeted theory-based behavioral counseling by their health care team.

### **Enhancing patient-to-patient (peer) support**

A variety of patient-to-patient support models have been studied, including group visits led by clinicians, emotional support groups, and peer coaches (63). All of these may improve outcomes among patients who attend (64–68), although many people with diabetes face the same barriers to participation in these programs as they do in traditional outpatient visits. Some patients concerned about privacy are uncomfortable in face-to-face group meetings and may prefer the privacy of talking on a phone. Telephone-based peer-support programs have their own limitations (69,70), and participants may be reluctant to share their telephone number or pay the cost of long-distance calls. From a health system perspective, telephone peer-support programs can be difficult to monitor and few,

if any, have been designed to interface with standard outpatient care.

In an ongoing study, researchers are evaluating the impact of an IBCT intervention that facilitates patient-to-patient peer support among people with diabetes using a specialized telephonic platform. The telephone service allows patients to 1) call their peer-support partner without charge, 2) enter a peer relationship without the need to share their home phone number or any identifying information, 3) designate times in which calls from their partner are blocked, 4) have all patient-to-patient calls blocked if they want to disenroll from the program, and 5) send and receive telephone messages with a care manager when questions require clinical input (21). Patients receive training in motivational interviewing techniques, and care managers reinforce peer relationships with group visits and by responding to patient voicemail queries. Using this personal and automated IBCT, investigators hope to build on the strengths of peer support in a way that addresses its weaknesses and allows the peer relationships to function under the supervision of the patients' health care team.

### **Supporting informal caregivers**

Informal caregivers may play an important role in supporting diabetic patients' efforts to follow self-management plans, identify early warning signs of acute illness, absorb the volumes of self-care education that patients need to stay well, and use formal health systems most effectively (71–73). However, growing numbers of older patients live far away from adult children and other social network members (74,75). While people outside the household may be willing to play a more active role, most lack the ability to systematically identify patients' health and self-care needs or to know how to help them in identifying and reaching behavioral goals. Researchers are developing IBCTs that may allow informal caregivers to take a more constructive role in diabetic patients' self-care. Using the service, patients receive regular health and behavioral monitoring either via automated telephone calls or the Internet and are given tailored automated feedback based on what they report. Patients' "CarePartners" receive e-mail reports based on the patient's assessments and have access to a comprehensive Web site with more detailed information about how they can help. Urgent health problems are

Table 1—Principles that should motivate future development of diabetes-focused IBCT

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**Look before you leap (but do not forget to leap).** Diabetes-focused IBCT research must include an active exchange between observational studies identifying key barriers to self-management and intervention trials identifying potential solutions.

**One size does not fit all.** A portfolio of tailored technologies will be required to address the needs of diverse populations, including patients without computers, non-English speakers, and those with health literacy deficits.

**Beware of “cool apps” (applications).** Technology per se is not a therapeutic service, and interventions must be based on strong behavioral theory.

**IBCT is most effective when it supports human contact.** New interventions should support patients’ primary care. Services that are seen as extraneous will not be maintained over time by either clinicians or patients with diabetes.

**Diabetes self-management is rarely patients’ primary life concern.** New services should be based on a holistic patient-centered model that takes patients’ full range of chronic conditions and the patient’s own agenda into account.

**Not all patients need IBCT.** Some patients do not need the added support IBCT can provide, while targeting patients with the poorest outcomes may not be the most effective way to allocate these resources.

**Translating innovations into new services requires collaborations between researchers, managers, clinicians, and people living with diabetes.** To move new interventions from bench to community, researchers should work with health system leaders to support program dissemination.

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reported to patients’ health care team via e-mail, fax, and pager. Both patients and their CarePartners receive structured guidelines to promote positive interactions that can lead to meaningful improvements in self-care behaviors. Pilot study results found that the service resulted in more targeted disease-specific communication between patients and their caregivers and that most would use a similar service if it were available as part of the patient’s usual care. Using this IBCT, patients may be able to access greater support for their day-to-day self-care, while caregivers have the tools they need to be more effective.

### Toward a thoughtful approach to IBCT development and implementation

**Look before you leap (but do not forget to leap).** Academic investigators have often frustrated decision makers with the axiom that “more research is needed” and have been more successful in identifying problems in diabetes care than possible solutions (Table 1). On the other hand, research on IBCT often has been supply driven, i.e., “a hammer in search of a nail.” While new IBCTs can be fascinating, the Internet, PDAs, telephone outreach, or other forms of IBCTs are only useful if they are vehicles for delivering thoughtful services that address real-world gaps in care. To develop truly effective interventions, researchers and program managers must proceed based on the whole spectrum of evidence, including:

1. Observational research to identify gaps in care, patient and clinician barriers to disease self-management, and the characteristics of patients’ environments that support success
2. Developmental research to insure that new technologies are designed in ways that are acceptable and accessible to patients and are sufficiently engaging so that patients will continue to use them over time
3. Interventional research designed to determine the efficacy of new modalities to support self-care and understand how programs work
4. Translational research designed to evaluate IBCT use in real-world settings, assessing not only its impact on behavioral or health outcomes but also other important criteria for success such as those described in the RE-AIM model (76)

**One size does not fit all.** People with diabetes differ dramatically in their clinical profiles, cultural backgrounds, psychosocial needs, and comfort with IBCT. Some patients would enjoy the opportunity for social interaction and mutual support afforded by peer-support interventions, whereas others would find these relationships frustrating, invasive, and anxiety provoking. Patients who are older or feel isolated may appreciate the increased contact with their loved ones made possible by a program that encourages structured follow-up by family members. But for those without such supports

or with negative family relationships, such a service would be impossible. From a health system perspective, leveraging the use of automated medication refill data or even clinic-based review of step counts from enhanced pedometers may seem trivial in some settings but beyond the reach of others who rely on paper-based records.

IBCTs are ideally suited to accommodate the diversity of patient needs and health system capabilities. Investigators should target the array of relationships illustrated in Fig. 1 and use technological tools that meet the needs of patients with little or no computer access or computer literacy (e.g., by communicating with them via telephone), as well as tools that take advantage of the Internet’s potential for rich multisensory communication using audio and video and for facilitating communication among groups of geographically dispersed people.

**Beware of “cool apps” (applications).** IBCT interventions developed in the early years of the Silicon Valley boom were often based on an implicit assumption that these tools were so novel and exciting that they were bound to make a difference. Since then, innumerable private companies have marketed proprietary behavior change technologies, often with the promise to deliver improvements in patients’ outcomes, which are rarely demonstrated in randomized trials. Entrepreneurs have indeed made progress in developing innovative IBCTs in ways that are often impossible given the funding and culture of academic medicine. Unfortunately, many of the services developed in the private sector have been difficult to integrate with outpatient care, are unsupported by third-party payers or patients’ pocket books, and are short on evidence that they can deliver the lasting impacts that make a difference in patients’ health. Large rigorous studies have shown that ongoing patient assessment without a plan for ensuring appropriate clinical follow-up is unlikely to improve outcomes (77–79), but many developers of IBCT continue to focus only on monitoring patients’ glucose levels, blood pressures, or other health indicators and feeding those data back to clinicians. In a review of more than 300 health behavior change programs on the Internet, investigators found that 40% met zero of the five goals of behavioral counseling outlined in the “5-A’s” (80),

and more than 75% met no more than two (81).

IBCT is no different from any other tool for improving patients' care, and its value depends on its goals, informational content, and appropriate patient targeting. There are a number of behavior change approaches (such as motivational interviewing [54]) and broader ecological perspectives (17) that can be useful in shaping IBCT communication so that it has the greatest possible benefit. As technologies make it possible for caregivers to assume new roles in patients' self-management support, these frameworks could be invaluable in not only designing IBCT tools themselves but also establishing effective follow-up between patients and others (e.g., patient peers, family members, or clinical pharmacists) who may have little or no training in behavior change support. On the health system level, innovations in IBCT have to make sense given the realities of outpatient practice, although many proprietary efforts have developed systems that do not fit with the culture of primary care. New initiatives will be far more successful if they take advantage of what we know about how clinicians and health systems process information (82,83).

### **Information technologies are most effective when they support human contact**

Many patients with diabetes (particularly older adults with type 2 diabetes) have years or even decades of unhealthy habits and are unlikely to change those habits based on a series of e-mails from their insurance company encouraging them to eat more fruits and vegetables. In contrast, IBCT closely linked with primary care will be used by patients over time and can improve their self-care behaviors and health outcomes. For example, Glasgow et al. (29) used clinic-based kiosks to allow patients to identify behavior change goals while they were waiting for their appointment. Written reports based on these behavioral assessments were used by both the patient and their clinician as the basis for behavior change planning, and the intervention had clinically significant and long-standing impacts on patients' health. Using another approach, several studies have shown that chronically ill patients can and will use IBCTs such as automated telephone calls or e-mail to provide valid information about their status over extended periods of time when this information is linked to fol-

low-up by a nurse or nutritional counselor (27,28,84–86). In each of these randomized trials, researchers demonstrated important improvements in patients' self-care, physiologic outcomes (including weight, glycemic control, and blood pressure), and even mortality risk.

Evidence is weaker regarding the types and intensity of human contact that could make IBCT effective, but patients need not receive follow-up directly from their physician or nurse care manager. Rather, family members and other patients (21) also may play an important role in supporting behavioral changes. The key element is likely to be the patient's sense that the communication is in the context of a relationship that is genuine, supportive, credible, and part of their vision for an overall plan to improve their diabetes-related health status under the direction of their health care team.

### **Diabetes self-management is rarely patients' primary life concern**

Patients with diabetes and their clinicians can be overwhelmed by the need to address comorbid conditions and other psychosocial concerns. Nevertheless, the majority of adults with diabetes have at least one comorbid chronic disease (87–89), and conditions such as depression, chronic pain (90–92), heart failure, and dementia often make diabetes self-care goals such as regular exercise and medication adherence almost impossible to attain (93). People may be "a patient with diabetes" while they are in a doctor's office, but diabetes is low on the list of characteristics of how they would define themselves (well below mother, policeman, church member, African American, friend, etc.). The advantage of IBCT communication is that diabetes services can enter the real world in which patients live. Efforts to do so, however, must find a way to provide the information and self-management support patients need in a manner that fits with their own life agenda. In short, new IBCT services must be based on a holistic patient-centered model that takes patients' full range of comorbid conditions and their own goals into account.

### **Not all patients need IBCT**

If appropriately designed and delivered, patients with a variety of sociodemographic characteristics, including patients with limited functional health literacy or English proficiency, will use IBCT as part of their diabetes care (94). Nevertheless,

the benefits of these technologies are not equally distributed across patients. Many patients already have the resources they need to effectively manage their illness and may receive little benefit from the types of support that are possible through IBCT. At the opposite extreme are patients with problems such as an unstable residence or other serious psychosocial needs who lack the basic resources to take advantage of this additional support. While patients with the poorest health status (e.g., diabetic patients with the worst glycemic control) are often targeted for new IBCT services, they may not be the patients who can benefit the most. Rather, IBCT may be of greatest benefit to the large number of patients with an interest and basic capacity to improve their diabetes care but who need the additional support for self-monitoring and self-management information that IBCT can provide. Health systems should carefully consider which patients could benefit from IBCT-based self-management services. Just as clinicians do not prescribe the same hypoglycemic drug in the same dose to all of their patients, we need to get more sophisticated in matching the right IBCT to the right patient at the right time.

### **Translating innovations into new services requires collaborations between researchers, managers, clinicians, and people living with diabetes**

In recent years, researchers have been increasingly encouraged to take greater responsibility for not only developing new service delivery strategies but also shepherding those services through the process of implementation and dissemination in real-world treatment settings. Investigators can play a vital role in this process, but clinicians and managers have the expertise, overall vision, and knowledge of health system constraints that are essential for translating research into practice. To develop effective plans for moving IBCT interventions from bench to bedside and bedside to community, researchers should work with health system leaders to understand their goals and support dissemination.

Despite the fits and starts of prior efforts, there are clearly enough successes in the world of IBCT research to justify further support by funders. Randomized trials will continue to be critical, but more basic research on IBCT will be needed to better understand how we can develop services that will be more acceptable to

patients and their clinicians. More research is needed not only on how to tailor behavioral messages using a given technology but also how to use a portfolio of different technologies in ways that can help communities that are diverse in their computer literacy and preferences. Studies that go beyond the one-to-one relationship between patients and their clinicians and use IBCT to leverage self-care supports via community organizations, other patients, or social network members may help fill the growing gaps in diabetes care. Regardless of the type of intervention, investigators must avoid research driven by the availability of “cool apps” and use sound theory to guide the ways in which new services are designed and evaluated.

### Conclusions

Most people with opinions about IBCT applications to diabetes care have fallen into one of two camps. 1) The believers have been strong proponents, and their conviction about the value of these services (although sometimes disproportionate to the evidence) has led some to push forward with research that has in fact proven the benefit of specific applications. 2) The skeptics have focused on the many very real limitations of IBCT, including the barriers to use among vulnerable patients, and IBCT's potential to detract from the humanistic elements of care. In the long run, neither side of this argument will win. Like any other generic strategy for delivering health care such as “medication” or “surgery,” global statements regarding the value of diabetes-focused IBCT will almost certainly be either inaccurate for many approaches or trivial in their generality. IBCTs are far too diverse and their applications far too varied to either hail their entrance into the world of diabetes care or be scorned as a distraction from true progress. Rather, thoughtful, realistic, and persistent development of new IBCTs based on sound principles will hopefully continue and chip away at some of the most daunting barriers to diabetes self-management support. Given the looming crisis in diabetes care, this can only be a positive thing.

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